DEEP DIVE

Long COVID is devastating and far from rare. As infections rise again, why are we still ignoring it?

As COVID cases rise once again, we're unprepared for the "mass disabling" event caused by long COVID

By PHILIP FINKELSTEIN

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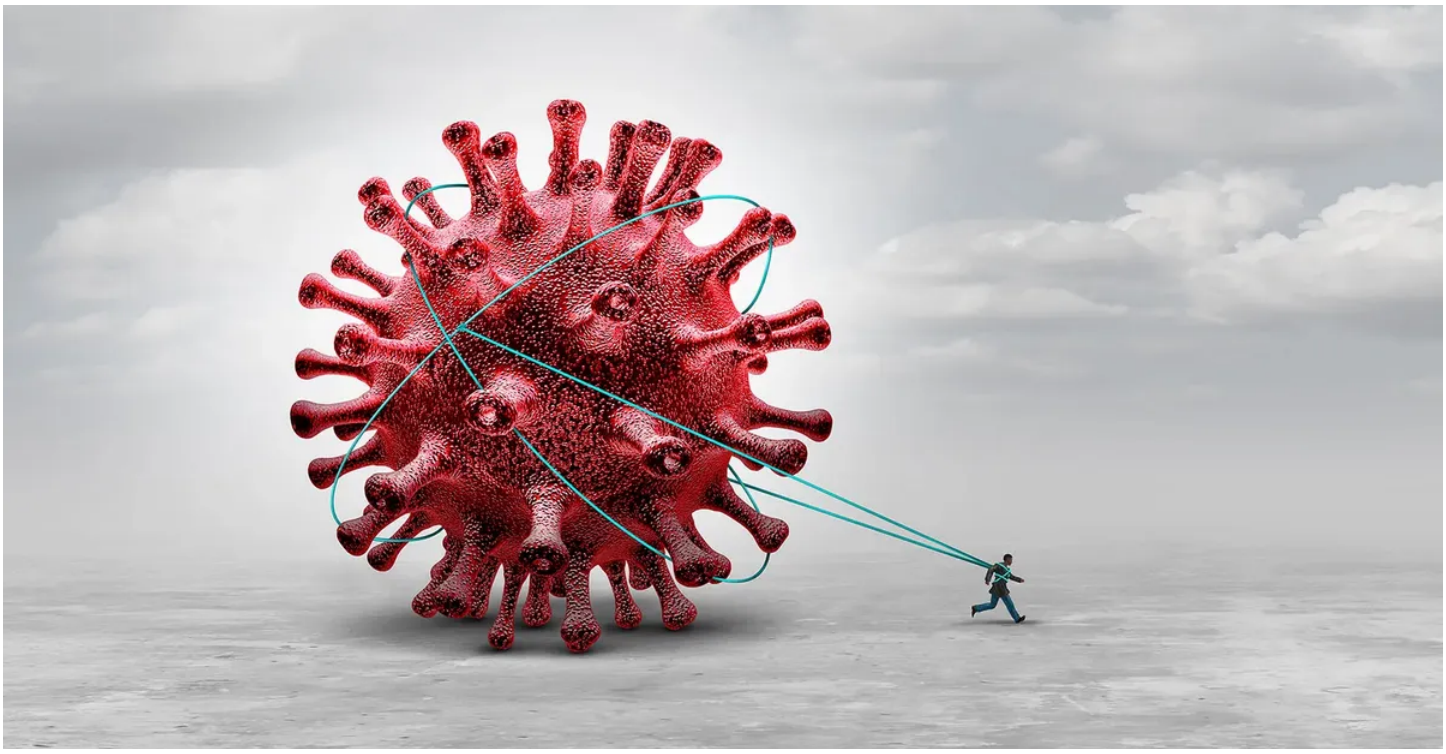

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On May 11, 2023, the federal public health emergency declaration for COVID-19 came to an end. Only a few months later, and cases are already starting to surge across the country again . This decision was made despite emerging science surrounding long COVID – a condition in which symptoms of the disease linger for months or even years. While the general public ignores and downplays the risk of SARS-CoV-2, the virus that causes COVID, long COVID may well prove to be one of the biggest health problems of the 21st Century, presenting a real risk that a secondary pandemic of chronic illness will be overlooked.

While things seem to be getting back to normal for most people, those with long COVID are still suffering – and this suffering will likely continue on indefinitely if nothing is done to change course.

As previously reported by Salon, an alarming scientific pattern is revealing itself across intersecting areas of research, which suggests that long COVID could be linked to neurodegenerative diseases like Parkinson's – having to do with the misfolding of alpha-synuclein proteins in the human nervous system. This misfolding is possibly triggered by

an initial COVID infection and can lead to unwanted accumulation of alpha-synuclein and the formation of Lewy bodies, resulting in neurological disorders.

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It's imperative that we follow this trail of science all the way through to the end. We can hope it's disproved, but ignoring it will leave us headed in the direction of disaster: debilitating, chronic, irreversible health conditions — or what some are calling a "mass-disabling event."

However, as a result of the Public Health Emergency Act expiring, COVID research and tracking has become more difficult. Coverage for tests, contact tracing, research funding, data reporting – it's all been thrown out the window, along with what little COVID precaution was left. Yet every COVID infection still puts an individual at risk of developing long COVID – which, according to the data, is increasingly likely among the less vaccinated and the more times you've contracted the virus.

It remains unclear whether certain COVID variants have greater potential to cause long COVID, but what is clear is that long haulers (people with long COVID) often report symptoms that line up with what those going through the prodromal (subclinical) phases of various brain diseases describe – meaning that long COVID patients are quite possibly experiencing the early stages of neurodegeneration.

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Take, for example, the prodromal stage of Parkinson's disease, which can last for decades prior to clinically-diagnosed Parkinson's. Before diagnosable motor deficits emerge, prodromal Parkinson's patients (though standard practice in medicine can't officially recognize them as such) report symptoms like loss of

smell, autonomic dysfunction (POTS, hypertension, hypotension, etc.), loss of sensation in the skin (small fiber neuropathy), gastrointestinal issues, urinary dysfunction, visual anomalies (retinal microvascular alterations), depression/apathy, sleep disorders, hormonal changes, and microclotting (amyloid fibrin microclots), among others.

These symptoms are often only recognized in connection with neurodegeneration retrospectively, after an official Parkinson's diagnosis, and correlate with increased risk of cardiovascular disease, diabetes and certain autoimmune diseases.

According to the National Institutes of Health (NIH) more than a decade ago (2011), 98.8% of Parkinson's patients interviewed in a study reported experiencing strange (prodromal) symptoms for an average of 10.2 years prior to receiving their initial Parkinson's diagnosis, which is consistent with Braak's hypothesis suggesting that Parkinson's is triggered by the inhalation of a pathogen like a virus or toxin.

Yet today, prodromal Parkinson's patients still can't get diagnosed until developing the characteristic motor deficits of clinical Parkinson's disease. This precludes them from treatments and therapies that could possibly prevent or delay the progression of the disease, or at least ease their suffering. Instead, their symptoms are dismissed and overlooked due to the lack of a detectable underlying biological mechanism. Essentially, they are told that the symptoms are in their head or unrelated to a more serious condition.

> **The parallels between the early Parkinson's symptoms outlined above and the symptoms reported by long COVID patients are undeniable.**

This is a clear failure of the medical community, as it leaves patients feeling lost, without a course of action. The root cause of their symptoms, as is the case for all early-stage synucleinopathies (diseases involving misfolded alpha-synuclein), can't be detected by standard diagnostics tools. And as diagnoses can't be made by doctors based on patient testimony alone, there are limited systems in place to effectively tackle the problem.

The parallels between the early Parkinson's symptoms outlined above and the symptoms reported by long COVID patients are undeniable. Although few want to admit it, these parallels likely go beyond two sides of the same coin. If the evidence bears out, then long COVID and prodromal Parkinson's could be the same side of the same coin. To be blunt, this means that long COVID patients may actually be miscategorized early-stage Parkinson's patients.

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But rather than entertain the idea that the consequences of COVID are far from over, we have collectively chosen to avoid the discussion of what could be causing long COVID. Sure, there's been plenty of reporting done on the personal and harrowing stories of those with long COVID – it'd be hard to avoid the topic altogether when there are millions out of the workforce due to long COVID – but, rarely, if ever, is a scientific explanation for long COVID proffered in plain language to the general public.

There's a reason as to why this science isn't being widely discussed. The hyper-politicization of COVID, brought about by then-President Trump at the pandemic's onset, coupled with years of pandemic fatigue, has made it a largely untouchable issue.

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This suppression of science is taking place across all levels of government and on both sides of the aisle, but for different reasons. Politicians have no desire to raise more alarm about COVID. On the Left, politicians risk being labeled alarmist, paternalistic or weak. Even popular left-leaning commentators like Bill Maher have been outspoken critics of the COVID response – a sentiment shared by a vast swathe of Americans who want their children in

school, the freedom to enter a store without a mask and the security of employment without vaccine mandates.

And on the Right, politicians who are generally all too willing to use fear to drum up outrage and support won't touch long COVID – despite how scary the link to Parkinson's might be – because it goes against the narrative they've pushed from the beginning: that reacting to COVID does more harm than good. So, that makes long COVID an issue that neither party wants to address. Better to secure your seat for the next election cycle, appease your constituents, then add to the basket of innumerable problems our country is already facing.

The decision to end the public health emergency gave license to individuals, companies and countries to stop caring about COVID.

The medical community has largely done the same thing: appease and equivocate. Just as prodromal Parkinson's patients would almost surely prefer to be diagnosed early on, even if there's nothing to be done in terms of treatment, than get bounced around the medical system for a decade, from specialist to specialist, before finally developing the necessary symptoms to be taken seriously, long haulers would greatly benefit from gaining a scientific understanding of what's causing their symptoms. Even many doctors may lack awareness when it comes to long COVID.

U.S. government and international institutions, too, have failed to properly address long COVID. The Center for Disease Control and Prevention (CDC), NIH and World Health Organization (WHO) all signed off on ending the public health emergency posed by COVID-19. Obviously, the world wants COVID to be over – and living in fear of a virus is far from compatible with the American ethos – but wanting something to be true does not make it so.

Regardless of Dr. Tedros Adhanom Ghebreyesus, the WHO chief, stressing that COVID remains a global threat, and similar such statements made by U.S. government officials,

the decision to end the public health emergency gave license to individuals, companies and countries to stop caring about COVID.

This is problematic on two fronts. First, considering COVID's tendency to mutate and the fact that only 20% of the U.S. population is up to date on their vaccines, a death surge could still occur under certain circumstances. Secondly, even if initial COVID infection is no longer a major threat, long COVID can still develop even after minor infection in otherwise healthy individuals.

> **After the SARS-1 pandemic of 2003, many survivors reported long-term mental health problems and chronic fatigue, symptoms of which were largely dismissed.**

We may have too much faith in these institutions. Whether it's the WHO's mishandling of Ebola, the CDC's own admittance of its botched pandemic response or the NIH's lack of urgency in establishing methods for detecting Parkinson's earlier on, the takeaway is an obvious need for institutional reform, as we continue to repeat the mistakes of the past.

After the SARS-1 pandemic of 2003, many survivors reported long-term mental health problems and chronic fatigue, symptoms of which were largely dismissed as post-traumatic stress disorder (PTSD). Scientists then started looking into underlying biological mechanisms that can cause long-term psychiatric morbidities. That was 20 years ago – a perfect timeframe for assessing whether any of the SARS survivors with long-term symptoms went on to develop a neurodegenerative disease, like Parkinson's.

While no one appears to have specifically looked into whether SARS-1 increased the risk of Parkinson's, studies do show that the long COVID of today shares trends with the long SARS of two decades ago. A longitudinal analysis of SARS survivors found that sequelae (secondary symptoms) persisted 18 years later. It was also found that sleep disorders were prevalent among chronic post-SARS patients, which is a strong indicator of

neurodegeneration. The H1N1 pandemic of 2009 also resulted in an uptick of sleep disorders. Therefore, perhaps the Mayo Clinic and Parkinson's Foundation observing a steady rise in the incidence of Parkinson's disease over the previous decades isn't entirely a coincidence.

The mistakes of the past are currently being remade with long COVID. The combination of institutional ineptitude and bureaucracy, the politicization and polarization of the COVID debate and pandemic fatigue has prevented very serious and legitimate science about the potential long-term dangers on COVID infection leading to neurodegenerative issues from entering the mainstream discussion.

The Disability Management Employer Coalition (DMEC) has been on the front lines of the long COVID battle, as they attempt to guide employers and employees through the challenges of upsurging disability due to long COVID, which has increased employer medical costs beyond that of any other chronic illness and intensified an already-problematic mental health crisis in America. According to Nomi Health, cited by DMEC, employer spending on long COVID is already 26% higher than the average spending on diabetes, a chronic illness that inflicts massive costs.

Projections indicate that long COVID will have a massive negative impact on the labor force and economy – costing the economy billions in lost wages. With an estimated 16 to 34 million Americans experiencing long COVID, a labor shortage is an area of real concern, as the chances of returning to full employment after a six-month absence due to injury or illness is around 55%. Extend that time to one year, and chances drop to 32.2%, and after two years, it falls to less than 5%.

KFF Health News reported that, with more than a million claims still unprocessed, the Social Security Administration (SSA) identified about 40,000 disability claims that "include indication of a COVID infection at some point." The severity of

"My biggest frustration is that we still struggle with a uniform definition of long COVID."

COVID's long-lasting effects should thus be a matter of national concern from an economic perspective, if not for the mere sake of public health.

After seeing so many severe COVID cases in their intensive care units, Dr. Panagis Galiatsatos, director of the Tobacco Treatment Clinic and associate professor of medicine at Johns Hopkins University and his colleagues started a post-COVID clinic to follow up with survivors dealing with complex lingering issues.

"What was fascinating," Galiatsatos told Salon, "is we would screen [patients] from head to toe, and sometimes we'd find complications from COVID that we could identify given a disease. Yes, you have lung scarring. Yes, you have high blood pressure from this. Yes, for diabetes. But then there was a cohort that all had tests come back unremarkable. I couldn't find a test to match their symptoms. And then suddenly we began to find others throughout the country."

Galiatsatos's clinic continues to care for long COVID patients today. When asked what kind of biomarkers he looks for when treating long COVID patients, he said, "My biggest frustration is that we still struggle with a uniform definition of long COVID. And to me, long COVID should be different from say a post-COVID complication. Post-COVID to me means if I can identify with a modern test a post-viral complication that isn't exclusive to COVID. Many viruses can do this." These sorts of conditions are typically treatable.

> **A diagnosis based on exclusion takes 3 to 6 months – that's a lot of time to be suffering and potentially unable to work without qualifying for disability.**

"From my standpoint," Galiatsatos went on, "long COVID is a disease of exclusion ... There's no biomarker for me to say: 'this is exclusive to long COVID' ... So the challenge we have is the fact that if we don't have a uniform, unified definition [of long COVID], you're going to get a lot of noise that's going to fail moving good trials ahead."

A diagnosis based on exclusion takes 3 to 6 months, according to Galiatsatos – that's a lot

of time to be suffering and potentially unable to work without qualifying for disability. Never mind the months it can take just to get into these types of clinics.

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The takeaway from this: there are two subtypes of "long COVID." One falls into the category of post-COVID complications. For example, respiratory-related issues due to lung scarring. The other is long COVID in a more concerning sense: a condition of chronic symptoms that can't be traced to an underlying source. It's this diagnosis by exclusion form of long COVID that has the potential to be the early stages of a neurodegenerative disease. But hopefully diagnosis by exclusion will not be the required approach for much longer, as diagnostically detecting misfolded alpha-synuclein non-invasively in living patients is becoming possible.

If long COVID has a neurological impact, then it'll be much harder to treat than current policy would have us believe. Right now, medical experts, employers, insurers and individuals are treating long COVID as a condition that can be solved through time and therapy — but what if this is not the case for millions of long COVID patients? What if COVID variants continue to cause long COVID and increase the risk of neurodegeneration in those who get infected?

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This would mean that acute COVID infection is likely the least of our worries. It'd mean physical therapy won't do much to address your long COVID symptom of post-exertional malaise. It'd mean that a fair number of long haulers won't recover sufficiently to return to work. It'd mean that 5 to 10, possibly 20 years, from now, COVID will exact its real toll, when Parkinson's-like diseases explode.

Galiatsatos said, "If we knew back in the '90s, for instance, what we know now about Epstein-Barr virus causing multiple sclerosis, you better believe we'd have done a lot more to prevent that from happening."

This is our chance to do more, to act strategically rather than reactively, but the window of opportunity is closing. So what can be done?

According to Galiatsatos, "We need to depoliticize COVID in general, stop with these political attacks. We need to come together and realize that long COVID is robbing people of their lives. They might be alive, may be existing, but they're not living."

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When pressed on specifics, he said, "Long COVID needs a multidisciplinary team ... But the healthcare system doesn't want that. If we can depoliticize long COVID and use it to transform medicine into what it should be for people when you have a disease that transcends one or more organs, then at least we could start caring for these patients now."

Other doctors and scientists at the world's most prestigious universities and medical centers should all be considered part of this multidisciplinary strategy for understanding the mechanisms of long COVID. Dr. David Putrino, Director of Rehabilitation Innovation for the Mount Sinai Health System, is currently working to develop innovative technology solutions for individuals in need of better healthcare accessibility. Mitchell Miglis of Stanford and Christopher Gibbons of Beth Israel Deaconess are both clinicians and researchers studying autonomic dysfunction. They've been focusing on the putative link between peripheral nervous system synucleinopathies, small fiber neuropathy, and autonomic dysfunction (especially POTS).

Then there's Birgit Högl at the Medical University Innsbruck, Austria, a clinician and

researcher focusing on rapid eye movement (REM) sleep behavior disorder and related biomarkers. This sleep behavior disorder is a strong predictor of a developing Parkinson's-like disease. Head of the sleep clinic and research group, and vice director of the Department of Neurology, she's involved in ongoing large-scale clinical trials exploring the relation between COVID, sleep disorders and neurodegenerative diseases. The combined research from figures like these will be the key to beating long COVID before a large portion of the population potentially develops an irreversible (neurodegenerative) disability.

Perhaps most crucially, a new skin test has proven effective at detecting alpha-synuclein clumps (the misfolded proteins in the nervous system that indicate a disorder), thereby providing a means of clinically diagnosing synucleinopathies like Parkinson's at far earlier stages. This needs the full weight of funding behind it, with the aim of rolling out these skin biopsies on long COVID patients. If atypical alpha-synuclein is detected across long COVID patients, it'd be convincing evidence that the condition is the beginning of a developing neurodegenerative disease. This could be a real game changer – something the world should genuinely be hopeful about. But, with the COVID emergency over, wide-scale skin testing may be harder to achieve. If possible, this diagnostic tool should be built into regular doctor visits for both the sick and healthy.

Similarly, recent research in the Lancet's Infectious Diseases revealed that the drug metformin, a diabetes medication, is an effective treatment for preventing severe COVID infection as well as long COVID. Findings showed that "Outpatient treatment with metformin reduced long COVID incidence by about 41%, with an absolute reduction of 4.1%, compared with placebo." The study concludes by stating, "Metformin has clinical benefits when used as outpatient treatment for COVID-19 and is globally available, low-cost and safe."

Efforts should be taken to make this drug known and readily available to the public. However, the non-emergency status of COVID again makes this a difficult task. As metformin should be used immediately following a positive COVID test, we need a system in place that encourages the continual monitoring of COVID infections. The U.S. will likely never live up to the impressive COVID data tracking of countries like Japan and Korea, but

as it stands now, there's almost no infrastructure in place to encourage self-monitoring. Even if an individual is COVID conscious (seemingly rare these days), taking metformin after a positive test would require a visit to the doctor's office to receive a prescription.

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Given metformin's effectiveness, and the relative lack of risk associated with the drug, if public officials aren't going to reinstate free COVID testing centers, then the least we can do is make metformin over-the-counter for easier accessibility.

"We need better public health messaging too," Galiatsatos said. The public must start learning about long COVID in a productive way and advocate for a change in strategy. The current state of things is leaving a lot of long COVID patients to feel abandoned, while the rhetoric surrounding the topic is engendering the generalized belief that many with long COVID are malingers rather than sufferers of a debilitating condition.

The evidence indicates that, at least in some cases, long COVID is primarily a brain disease. Admitting this is the first step to carrying out a proactive and fully-informed approach to living in a world with endemic COVID.

As research progresses, our understanding of long COVID will improve, guiding public policy decisions and speeding up responses to emerging COVID variants. Determining the biological mechanisms underlying long COVID will facilitate the rapid development of diagnostics tools and treatments. At present, it's vital, however, that we take heed of the worst-case scenario – long COVID may be a neurodegenerative condition and a precursor to Parkinson's (or a similar) disease. Let's look into this like our lives depend on it.

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By **PHILIP FINKELSTEIN**

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